



Information and Consent Form

Activating Lived Experience Leadership – Focus Group

Dear Participant,

You are invited to participate in a research project: **Activating Lived Experience Leadership**

We are asking if you would like to engage in a number of audio-recorded focus groups about your knowledge and experience as a person who is a lived experience leader or advocate.

The Activating Lived Experience Leadership (ALEL) research project is a partnership between the Lived Experience Leadership & Advocacy Network (LELAN) and University of South Australia's Mental Health and Suicide Prevention Research Group (MHSPRG). The research project is the most significant investment to date in the area of inquiry in South Australia and has been funded by the Fay Fuller Foundation for two years.

Participation in this research is completely voluntary. If you do not wish to take part, you do not have to. If you decide to take part, you will be given this Participant Information and Consent Form to sign and a copy to keep.

Before you decide whether or not to be involved, it is important that you are clear on what you are being asked to do and the benefits of being involved. Your decision whether to take part in the research will not affect your relationship with the ALEL research project team members.

What is the purpose of this research?

The broad purpose of the ALEL research project is to examine and describe key aspects of lived experience leadership and how it can be better connected, recognised and used in South Australia. The key aspects that we will explore include, definitions of leadership, the different roles that leaders take on, the conditions and supports that help with influence and change and the learning resources that help leaders. We would like to learn about your understanding and experience of these areas.

What will I need to do if I participate?

You will be asked to take part in two audio-recorded face-to-face focus groups with members of the research team. You will also be asked to participate in an online discussion group (time commitment for this part of the project will be up to two hours). Topics covered will include definitions of leadership, roles, influence and change, and learning resources. The face-to-face focus groups will be conducted by members of the research team (Professor Nicholas Procter, Dr Mark Loughhead or Ms Ellie Hodges) and may take up to 90 minutes. The audio-recorded focus groups will be transcribed. Data (posts) from the online focus groups will also be collected and used to gain insight into the topics discussed. The two face-to-face focus groups will occur approximately one month apart, with the online group being open to the focus group participants following the first focus group. To recognise your time and costs in being involved in the project, a gift card of \$45 will be provided for participants in the first round of focus group discussions.

Who is being invited to participate in the research?

You can participate in this study if 1) you have lived experience of mental health related distress or are a carer of a person experiencing mental health related distress and 2) you are active in contributing to improving services or community awareness. You may be active in advocacy, peer networks and support, community education or advisory roles.

The project has a focus on diversity and seeks to involve active lived experience people who may also be

- Gender and sexually diverse people
- Young people – aged between 15-24 years
- Culturally and linguistically diverse people
- Older people
- People living with disability
- People who live in non-metropolitan areas of South Australia
- People who are mental health clinicians

We are planning to hold focus groups in rural and metropolitan settings.

How will my confidentiality be maintained?

Before the focus group commences you will be asked to choose a pseudonym to be used during the discussion. This will help to keep your identity anonymous while recording and reporting the results. All participants will be required to sign a consent form which will include the following statement: 'I understand that if I participate in a focus group that I will be required to maintain the confidentiality of the other participants' identities and keep confidential anything that is said by any participant in the focus group.' Any personal information obtained from you will only be used for the purposes of this research project and with your permission, and no information which could lead to the identification of any individual will be released, unless in the unlikely event that disclosure is required by law. Direct quotes from what you have said may be published in a report or a journal article, but you will not be able to be identified.

During the project all data (including the transcript and audio recording of the focus group) will be stored electronically on the password protected UniSA computer server and in paper copy in a locked office at the Mental Health and Suicide Prevention Research Group offices at the University of South Australia. At the end of the research project, data will be securely stored for a period of five years (University of South Australia guidelines: Ownership and Retention Policy) on the secure UniSA server and in a locked compactus in a locked room (University of South Australia, City East Campus, School of Nursing and Midwifery) and will only be accessed by the research team. After the five-year period, all digital files will be erased, and the USB and paper copy documents destroyed and deposited in a confidential bin.

If you are between the ages of 15 and 17 a parent guardian will be required to also sign the consent form.

During the project the focus group audio recording will be stored electronically on a password protected computer in a locked office at the Mental Health and Suicide Prevention Research Group offices at the University of South Australia. At the end of the research project, the transcript and recording of the focus group will be stored on an encrypted USB for a period of five years (University of South Australia guidelines: Ownership and Retention Policy) in a locked compactus in a locked room (University of South Australia, City East Campus, School of Nursing and Midwifery) and will only be accessed by the research team. After the five year period, all digital files will be erased from the USB and the USB destroyed and deposited in a confidential bin.

What if I want to withdraw from the research?

You are free to withdraw from the research at any time before participating in the focus group. You may refuse to answer a question during the focus group, or walk out during the focus group and leave if you are not feeling comfortable. If you do withdraw during the study, the data captured up to that point will still be included in the study. Withdrawing from the research will not affect your status in any way.

Are there any risks?

There is a small risk associated with engaging in the focus group, but no more than what you would experience in everyday life. However, if you experience any distress at any later time, please contact one of the following:

- Your local GP
- Lifeline Australia – 13 11 14 or <https://www.lifeline.org.au/> (available 24/7)
- Suicide Call Back Service – 1300 659 467 or www.suicidecallbackservice.org.au (available 24/7)
- Beyondblue – 1300 22 4636 <http://www.beyondblue.org.au/> (available 24/7)
- MensLine Australia – 1300 78 99 78 or <https://www.mensline.org.au/> (available 24/7)
- Mental Health Triage – 13 14 65 (available 24/7)

What are the merits of being involved?

This research will provide important information about the nature of lived experience leadership and contribute to improved understanding about leadership roles, change and supportive environments. This understanding will also be used to generate learning resources and training opportunities. It will also be used to strengthen networks where lived experience leaders contribute to progressive change in community mental health.

When will I find out the results?

If you would like a summary of the anonymous research findings please contact Dr Mark Loughhead at the end of the research project: E: Mark.Loughhead@unisa.edu.au; P: 08 8302 1267.

What next?

If you would like to find out more information or to participate, please contact:

Dr Mark Loughhead: E: Mark.Loughhead@unisa.edu.au; P: 08 8302 1267;

Ms Heather McIntyre: E: Heather.McIntyre@unisa.edu.au; P: 08 8302 1132.

If you agree to participate please sign the consent form below and return it the research team on the day of the focus group.

This project has been approved by the University of South Australia's Human Research Ethics Committee (202513). If you have any ethical concerns about the project or questions about your rights as a participant, or should you or any third parties wish to lodge a complaint about either the study or the way it is being conducted, please contact the Executive Officer of this Committee – Ms Vicki Allen (P: +61 8 8302 3118; E: humanethics@unisa.edu.au).

Kind regards,

The research team

Name	Telephone number	Email address
Dr Mark Loughhead ¹	08 8302 1267	Mark.Loughhead@unisa.edu.au
Ms Ellie Hodges ²	0422 888 157	ehodges@lelan.org.au
Professor Nicholas Procter ¹	08 8302 2148	Nicholas.Procter@unisa.edu.au
Ms Heather McIntyre ¹	08 8302 1132	Heather.McIntyre@unisa.edu.au

¹ Mental Health and Suicide Prevention Research Group, School of Nursing and Midwifery, University of South Australia.

² Lived Experience Leadership & Advocacy Network

Activating Lived Experience Leadership – Focus Group Consent Form

This research project has been approved by the University of South Australia’s Human Research Ethics Committee. If you have any ethical concerns about the research project or questions about your rights as a participant please contact the Executive Officer of the UniSA Committee, Tel: +61 8 8302 3118; Email: humanethics@unisa.edu.au.

SECTION 1: Contact and research project details

Researcher’s Full Name:	Dr Mark Loughhead
Contact Details:	P: 08 8302 1267; E: Mark.Loughhead@unisa.edu.au
Protocol Number:	202513
Research Project Title:	Activating Lived Experience Leadership

SECTION 2: Certification

Participant Certification

In signing this form, I confirm that:

- I have read the Participant Information Sheet and the purpose of the research project has been explained to me. I understand and agree to take part.
- I understand the purpose of the research project and my involvement in it.
- I understand that I may not directly benefit from taking part in this research.
- I understand that I can withdraw from the research at any stage prior to the focus group taking place and that this will not affect my status now or in the future.
- I confirm that I am 15 years of age or over.
- If you are between the ages of 15 and 17 a parent guardian will be required to also sign the consent form.
- I understand that I will be required to participate in several audio-recorded focus group of up to 90 minutes.
- I understand that if I participate in a focus group that I will be required to maintain the confidentiality of the other participants’ identities and keep confidential anything that is said by any participant in the focus group.
- I understand direct quotes from the focus group of statements I make could be used in publishing responses in a report or a journal article. The responses are made under a pseudonym to minimise risk to being identified.
- I understand that although every care will be taken to guard my anonymity there may be a risk that my responses will be identifiable and I am aware of that risk.
- I understand that I will receive a \$45 gift card as an honorarium for attending the focus groups.
- During the project the focus group audio recording will be stored electronically on a password protected computer in a locked office at the Mental Health and Suicide Prevention Research Group offices at the University of South Australia. At the end of the research project, the transcript and recording of the focus group will be stored on an encrypted USB for a period of five years (University of South Australia guidelines: Ownership and Retention Policy) in a locked compactus in a locked room (University of South Australia, City East Campus, School of Nursing and Midwifery) and will only be accessed by the research team. After the five year period, all digital files will be erased from the USB and the USB destroyed and deposited in a confidential bin.

Participant Certification

<i>Participant Signature</i>	<i>Printed Name</i>	<i>Date</i>

Parental Guardian Certification

<i>Parental guardian Signature</i>	<i>Printed Name</i>	<i>Date</i>

Researcher Certification

I have explained the research to subject and consider that he/she understands what is involved.

	Dr Mark Loughhead	
<i>Researcher Signature</i>	<i>Printed Name</i>	<i>Date</i>